

ABOUT THIS AGENDA



Through regional youth forums, focus groups, surveys and other input gathering events, we regularly collect input from young people across the state with disabilities and/or involvement in systems such as: mental health, child welfare, addiction recovery, juvenile justice, and special education. This allows us to gain insight on topics important to young people and explore what helps and what harms in systems and services. This agenda represents the voices of young people in our network and the issues that we regularly work to address.

ABOUT YOUTH POWER!



YOUTH POWER! is Families Together's statewide youth network that is run for and by youth and young adults. We are a statewide network of young people who have been labeled and are seeking change. Together, we have decided to speak up about our experiences because nobody knows what it is like for us better than we do. Through peer-to-peer mentoring we empower young people to be active citizens who are aware of government operations, their rights, and the ability to influence policies, practices, regulations, and laws. We are young people helping other people, ensuring the availability of self-help and peer support so that young people get the support they need with the respect and dignity they deserve.

2020 PRIORITIES



**Increase Youth
Guided Practice**



**Expand Youth
Peer Support**



**Rights &
Protections**



**Youth Serving
Systems**



**Education &
Employment**



**Independent Living
& Transportation**

INCREASE YOUTH GUIDED PRACTICE



"Young people need to be invited and prepared for all meetings decisions are being made at"

All organizations and agencies that support young people must prioritize the development and enhancement of processes for young people to guide and provide input into the services they receive, including the development of Youth Advisory Councils.

- Ensure young people are aware of their right and opportunity to guide the services they receive.
- Develop policies, protocols, and best practices to ensure authentic youth involvement across systems.
- Provide additional funding to support statewide, cross-systems efforts to identify and coordinate youth voice beyond current capacities.

EXPAND FORMAL AND INFORMAL YOUTH PEER SUPPORT

Develop cross-systems peer supports available to young people and their families, both formally and informally, in their communities that is timely, affordable, and available regardless of system or insurance status.

- Expand and integrate formal and informal Youth Peer Support into all children's services/programs regardless of insurance status and provide funding to support, expand, and maintain these programs.
- Increase and braid funding across agencies to support the cross-systems work necessary to address the complex needs of young people and the successful integration of the youth peer workforce.
- Develop a clear process through which the Youth Peer Services Advisory Council will advise the state on the development of cross-systems youth peer support and training services.
- Provide funding to create more community places statewide that offer informal peer support, youth-led activities, and educational/training opportunities.

"Peer support needs to be included in all services. Everything is easier when you are speaking to someone like yourself"



"We need more free and safe places in the community to have fun . We need NORMALCY!"

RIGHTS AND PROTECTIONS

BULLYING | DISCRIMINATION | CONSENT | RESTRAINT & SECLUSION | ENFORCEMENT | #STOPTHESHOCK

BULLYING

Strengthen anti-bullying initiatives and accountability within schools, communities, and service systems.

- Support and develop bullying prevention and intervention programs not only in schools but across state systems, in local communities and on the internet. These programs must include peer mediators and ensure the current bullying laws are fully implemented.
- Schools need to be held accountable for abiding by current bullying laws, including the Dignity for All Students Act signed into law in 2010, and following through on addressing reported instances of bullying.
- A method for identifying the performance levels of schools must be developed collaboratively by young people, school administrators, and other stakeholders to further support accountability regarding the enforcement of bullying legislation.
- Education for young people and their families on their rights and how to report bullying and cyber harassment must be increased.



"Believe young people every time, don't take their claims of bullying, unsafe environments, or unsafe for themselves as 'kids will be kids'."

DISCRIMINATION

Strengthen anti-discrimination efforts, LGBTQIA+ Rights and Protections, and Address Disproportionality.

- Cultural competency training regarding all protected classes (race, national origin, disability, gender identity, sexual orientation, etc.) must be required of all employees in human and social service settings including those who are not direct service providers.
- Increase opportunities for young people representative of protected classes and system experiences to participate in workforce development and training events as educators pertaining to their culture, identities, and experiences.
- All health and human services must be equipped to support and integrate LGBTQIA+ youth with the highest level of respect.
- The name, gender, and pronouns transgender and non-binary youth identify with must be respected and utilized in community, residential and hospital settings.
- NYS must work to address racial disparities and disproportional representation of young people of color and young people with disabilities in institutional settings and across systems. Services must be offered equally to all people. We urge the State to take a data-driven approach to disproportionality to track improvements, publish results and share best practices across counties.



"We need support and acceptance."

RIGHTS AND PROTECTIONS CONTINUED

CONSENT

Assure informed consent and that young people are empowered and supported in making decisions and addressing concerns with services.

- Ensure young people are informed of their rights, including bodily autonomy, in a manner that is developmentally appropriate and that those rights are both protected and can be exercised without fear of retaliation.
- Ensure young people are provided phone numbers and website addresses for advocacy and protection agencies.
- Information regarding young people, their services, and their diagnoses must be provided in a way that is youth-friendly and ensures their understanding.
- Ensure education and informed choice for young people regarding medication and treatment planning.
- Create systemic approaches to address the use of prescribed medications to control behavior in institutional and congregate care settings.



"I want things more broken down; They assume everyone knows what is being talked about"

"Seclusion isn't a cure. We need access to the outer world. Sure, boundaries should be set but feeling alone is a poison to the mind."

RESTRAINT & SECLUSION

Eliminate restraint and seclusion across ALL systems.

- Provide funding, guidance, and support for the use of comfort and sensory tools in all settings.
- Standardize training and reporting requirements across all systems.
- Mandate reporting and monitoring of restraint and seclusion instances in all state licensed programs.
- Ensure all children's services are trauma informed and provide funding to support training in these practices throughout all systems.
- Continue cross-systems partnerships to address the systemic issues leading to instances of restraint and seclusion. Ensure self-advocacy groups and all levels of government and service provider leadership are engaged.
- Ensure youth are informed of and provided with effective tools for reporting instances of restraint and seclusion and addressing issues/concerns with the actions of staff in these instances.

ENFORCEMENT OF LAWS

Ensure enforcement and implementation of the ADA, IDEA, Olmstead, and the NYS Human Rights Law

- Increase efforts to systematically address the implementation and enforcement of these laws.
- Increase social marketing and public information of available advocacy and reporting resources for individuals with disabilities and their families.

#STOPTHESHOCK

Stop the flow of NYS tax dollars to the JRC and ensure their practices, which have been condemned as torture, are not used on youth.

- Ensure parents/caregivers are fully educated on alternative options for support.
- Shift the flow of tax dollars to address the lack of sufficient services in New York State.
- Continue efforts to reduce out of state placements. These efforts must maintain the Executive Office's attention.
- NYS must support banning the use of GED devices.

MENTAL HEALTH

Ensure cross-systems community-based mental health care is available, affordable, and sustainable.

- Ensure adequate fee-for-service rates for children's clinics to maintain quality services and a well-trained workforce.
- Make community-based services available and known before a crisis or threat of hospitalization or residential placement.
- Ensure community-based services for Medicaid recipients are available in all counties in New York State.
- Improve coordination with the education system to ensure youth transitioning from residential and inpatient settings are getting an appropriate education and earn credits that will lead to a diploma.
- Increase funding for youth-guided, family-driven anti-stigma campaigns.
- Enhance statewide suicide prevention efforts and ensure they are trauma-informed, youth-guided, and community-based.
- Increase the availability of integrated supportive housing units designed for young adults.
- Phase out and eliminate the use of point systems.
- Increase opportunities for self-guided treatment, creativity, and community-based activities and supports.



"STOP POINT SYSTEMS!"

"They have to connect with us where we are at, both with interests and literally"

ADDICTION RECOVERY

Increase and expand youth-guided, recovery-oriented supports and education.

- Provide small grants and incentives for better linkages between treatment and prevention providers with youth development programs, after school activities, and community centers.
- Improve family engagement in treatment by increasing the amount and availability of treatment facilities and community-based services across the state. Additionally, innovative approaches to family engagement, including video communications, must be explored and supported.
- "Just Say No" to outdated anti-drug campaigns and establish new practices and innovative ways to support anti-drug efforts and informed decision-making in collaboration with young people.
- Increase the availability of opportunities and events in the community that provide a safe and sober environment for young people to socialize with their peers.
- Improve coordination between substance use and mental health programs.



"There needs to be more up to date anti-drug efforts because the old way of getting the message across doesn't connect with this generation"

"Substance use and mental health programs need to work better together"

DEVELOPMENTAL DISABILITIES

Improve the availability and coordination of services, knowledge of supports, and efforts to consult actual autistics first on matters of policy and legislation

- Improve the collaboration between OMH and OPWDD for young people to receive both mental health and developmental disability services and ensure supports are coordinated in a timely fashion.
- Increase young people's knowledge of support services, including housing support and opportunities to support independent living.
- We insist that government officials and legislators consult with autistic run groups and organizations on matters of policy and legislation.
- Protect and expand Self-Directed Services so that people with disabilities, including young people are able to get the support they need to live independently in a way that works for them.



"Help youth with developmental disabilities become more independent. Housing, relationships, finances. I want to Pick My Own Clothes! "

CHILD WELFARE

Strengthen programs and invest in targeted community-based supports that utilize Family and Youth Peer Advocates with lived experience.

- Expand primary prevention and define eligibility for preventive services as broadly as possible.
- Increase the Family First Transition Fund to strengthen family-based foster care.
- Dedicate an open-ended funding stream to KinGAP similar to adoption subsidies.
- Establish an Ombudsman for birth parents, foster parents, kin, and young people in care.
- Ensure foster youth are prepared, supported, and educated as they transition into adulthood and independent living.

"Put the CARE back in foster care!"

REFORMING THE JUSTICE SYSTEM

Invest in a restorative system that emphasizes developmentally appropriate approaches and increase efforts to improve relations between law enforcement and the community.

- Implement and improve the Raise the Age law.
- End the use of solitary confinement in Adolescent Offender Facilities.
- Address disparities that include an over-representation of young people of color and disability status.
- Increase regular and consistent youth advisory methods within juvenile justice.
- Strengthen and expand protections for court involved youth up to age 25.
- End the adult incarceration of youth.
- Pass the Humane Alternatives to Long-Term (HALT) Solitary Confinement Act.
- Increase community programs for diverse groups of young people to have positive interactions with the police and provide opportunities for young people to inform these practices.

EDUCATION

Establish individualized supports and pathways that reflect the diverse needs, strengths, and experiences of young people.

- Develop performance-based assessments and portfolio-based graduation options for students to demonstrate their knowledge and skills in contexts that are familiar and relevant to their high school experiences in lieu of each regents exam.
- Pass the Solutions Not Suspensions Act which limits out-of-school suspension, requires positive intervention strategies whenever feasible, and ensures that police in schools are not permitted to intervene in everyday student discipline matters.
- Support legislation requiring that Disability History Awareness be taught as part of the required NYS curriculum and increase self-advocacy resources and education in schools.
- Increase knowledge and support for ALL educational and vocational opportunities after high school, including trade schools.
- Increase access, availability, and awareness of assistive technology and ensure students are educated on their rights regarding their use.
- Ensure young people are invited to their IEP meetings, empowered, prepared and able to participate without negative consequences in accordance with NYS Law.



"People need to be supportive of choices and not try to "scare" us into the steps that they see fit"

INDEPENDENT LIVING & EMPLOYMENT

Increase support and education for young people as it pertains to independent living, employment, and housing.

- Increase education and training opportunities surrounding independent living skills, such as financial literacy.
- Utilize young people to train workforce professionals on youth engagement and supporting self-advocacy.
- Continue to enhance integrated supportive employment programs for young people with disabilities.
- Create more opportunities for youth in foster care to gain employment skills and job placements.
- Continue tax incentives for businesses employing young people with disabilities and experience in systems such as foster care, juvenile justice, mental health and addiction treatment.
- Provide education for young people on using public transportation and finding housing that fits their needs.
- Increase the availability of accessible transportation, including ride sharing services.

"We need help making connections to people that can help us once we are out on our own"

"Learning how to pay bills, grocery shop, do laundry, find jobs. How do we find safe and affordable housing?"

CONSUMER DIRECTED CHOICES

Protect and expand consumer directed choices for people with disabilities, including young people.

- The state must protect access to Consumer Directed Personal Assistance (CDPA) and reform managed care to protect equitable reimbursement and ensure consumer choice and quality care.
- Expand CDPA from being a Medicaid only program to all New Yorkers so that all in need of these services are able to access them.
- Establish a dedicated information line to ensure that those in need of CDPA are able to receive timely and accurate information.
- Community First Choice funds must be reinvested in community-based services.



HEALTHCARE

Improve our healthcare system so that it is culturally competent, family-driven, youth-guided, and guarantees access to both physical and mental health care.

- Ensure young people have meaningful participation in efforts that alter the health care system.
- Expand adolescent sexual health education programs to include substantive information on young people with disabilities.
- Create guidance for programs and families in navigating these discussions in collaboration with all stakeholders.

(Youth need) "Real services that will teach young people about how to: Build real relationships, how to take care of our bodies, how to love."

ACRONYMS

ACCES-VR: Adult Career and Continuing Education Services-Vocational Rehabilitation

ADA: Americans with Disabilities Act

CCF: Council on Children and Families

CDPA: Consumer Directed Personal Assistance

CFTSS: Child and Family Treatment and Support Services

DCJS: Division of Criminal Justice Services

DDPC: Developmental Disabilities Planning Council

DOH: Department of Health

DOL: Department of Labor

FPA: Family Peer Advocate

GED: Graduated Electronic Decelerator

HCBS: Home and Community Based Services

IEP: Individualized Education Program

JRC: Judge Rotenberg Center

LGBTQIA: Lesbian, Gay, Bisexual, Transgender, Queer or Questioning, Intersex, and Asexual

MCO: Managed Care Organization

MRT: Medicaid Redesign Team

NYSED: New York State Education Department

OASAS: Office of Addiction Services and Supports

OCFS: Office of Child and Family Services

OMH: Office of Mental Health

OPWDD: Office for People with Developmental Disabilities

SOC: Systems of Care

SSA: Social Security Administration

SSI: Supplemental Security Income

TAY: Transition Age Youth

WIOA: Workforce Innovation and Opportunity Act

YPA: Youth Peer Advocate